

REPORT ON THE PROCEEDINGS OF THE WORKSHOP

TO DISCUSS STRATEGIES OF INVOLVING

PERSONS WITH DISABILITIES

IN DISTRICT HEALTH ACTIVITIES

AND INITIATIVES

HELD

AT PELIKAN HOTEL MBARARA, UGANDA

24TH – 26TH JUNE 1999

FUNDED BY EDF/RHP AND ORGANISED BY NUDIPU

Report compiled by Martin Ssenoga

REPORT ON THE PROCEEDINGS OF THE WORKSHOP TO DISCUSS STRATEGIES OF INVOLVING PWDs IN DISTRICT HEALTH ACTIVITIES AND INITIATIVES

Venue PELIKAN HOTEL MBARARA

Dates: 24th -26th June 1999

LIST OF PARTICIPANTS:

- | | | | |
|-----|--------------------------|---|---|
| 1. | Hon. Alex Ndeezi | - | Chairman NUDIPU/Member of parliament. |
| 2. | Hon. Hood Katuramu | - | Member of Parliament |
| 3. | Dr. Alice Nganwa | - | Ministry of Health |
| 4. | Dr. Kazibwe S. R.K. | - | Ag. Director District Health Services Kalangala |
| 5. | Mr. Matia. M. Lukumbira | - | Rep. Director District Health Services Masaka |
| 6. | Mr. Danieli Karuhanga- | - | Board Member NUDIPU. |
| 7. | Dr. Kisubi Mohammed | - | Ag. Programme coordinator EDF/RHP |
| 8. | Ms. Mwebaze A. J. | - | Sec. Social Services Sembabule. |
| 9. | Mr. Urban Banturaki | - | Sec. Social Services Ntungamo |
| 10. | Mr. Kaddu Joseph | - | Rep. Sec. Social Services Kalangala |
| 11. | Ms. Liz Moulton | - | 'OURS' for PWDs Mbarara |
| 12. | Ms. Bakeine Alice | - | Sec. Soc. Services Kabale |
| 13. | Capt. David Matovu | - | Sec. Soc. Services Rakai |
| 14. | Ms. Mwesigwa Prisca | - | District Health Educator |
| 15. | Mr. Galiwango Charles | - | Councillor Masaka |
| 16. | Mr. J.B. Mukasa | - | D. Union Masaka |
| 17. | Mr. Tushangomujuni. Joas | - | Councillor Ntungamo |
| 18. | Mr. Nsamba Joseph | - | D. Union Kalangala |
| 18. | Mr. Ngirumpatse D. | - | Councillor Kisoro |
| 19. | Ms. Nizeyimana Pamela | - | Councillor Kisoro |
| 20. | Ms Kwizera Imelda | - | Councillor Kisoro |
| 21. | Mr. Ahimbisibwe William | - | Councillor Mbarara |
| 22. | Ms. Namubiru Juliet | - | Councillor Kalangala |
| 23. | Mr. Baingana F. R. | - | Councillor Bushenyi |
| 24. | Ms Burisadi Justine | - | Councillor Bushenyi |
| 25. | Mr. Beesiga John | - | D. Union Mbarara |
| 26. | Mr Ayesigye Moses | - | D. Union Ntungamo |
| 27. | Ms Aturinda Rehema | - | D. Union Kabale |
| 28. | Mr. Ben Twesigye | - | D. Union Rakai |
| 29. | Mr Herbert Misheru | - | Councillor Rukungiri |
| 30. | Ms Kyomugisha Joy | - | Councillor Rukungiri |
| 31. | Ms Namayengo Harriet | - | Councillor Rakai |
| 32. | Mr Kashugwa C | - | Comm. Services Officer Ntungamo |
| 33. | Ms. Kiggundu Josyline | - | Councillor Rukungiri |
| 34. | Mr Mustafa Ssali | - | D. Union Masaka |
| 35. | Nnalongo Otafiire | - | Sec. Social Services Bushenyi |

36	Mr Rwabiito Clemence	-	'OURS' Mbarara
37	Mr Banjo Masereka	-	Councillor Kasese
38	Ms Kabwizi Jolly	-	Councillor Mbarara
39	Ms Katusiime Josyline	-	Helper
40	Dr Mayanja Bernard	-	Councillor Mbarara
41	Mr Sam Wekesa Masaba	-	DRO Mbarara
42	Mr Swaleh Mawa	-	D.Union Kabale
43	Ms Kobusingye Anne	-	Councillor Kabale
44	Ms Musimenta Catherine	-	Helper
45	Mr Bakengana Josephat	-	Helper
46	Mr Geoffrey Onono	-	Interpreter
47	Ms Natukunda Brenda	-	Helper
48	Ms Tuhairwe Juliet	-	Interpreter
49	Mr. William Nokrach	-	Facilitator NUDIPU
50	Mr Ssennoga Martin	-	Rapporteur

D.Union refers to District Unions of Persons with disabilities

OPENING REMARKS FROM THE AG. EXECUTIVE DIRECTOR OF NUDIPU

The workshop opened with a few remarks from the Ag. Executive Director of NUDIPU who thanked the participants for turning up in such a big number. He explained that the workshop was organised by NUDIPU and funded by European Development Fund/Rural Health Programme (EDF/RHP)

He hoped that the workshop would be the beginning of a successful collaboration between PWDs and EDF/RHP.

WORKSHOP ORGANISATION

Workshop objectives

- The workshop's objectives were to discuss ways and means of involving People with disabilities in district health activities and initiatives in the EDF/RHP area of operation. EDF/RHP started working in Western Uganda in 1985 to date but in spite of the tremendous achievements they have made, people with disabilities seemed ignorant of the activities and initiatives they have been undertaking. The purpose of this workshop therefore was to find strategies of involving PWDs in district health activities in general and those funded by EDF/RHP in particular.
- Discuss strategies of integrating PWDs in Health activities and initiatives.
- * Discuss how EDF/RHP can assist PWDs in their health initiatives
- Agree on way forward

PARTICIPANTS' EXPECTATIONS

- * To learn more about EDF/RHP. What EDF/RHP can support and how to get access to that support.
- * To find out problems affecting PWDs in Health provision.
- * To discuss ways of involving PWDs in planning and implementation of Health programmes.
- * Active participation of all participants
- * To find out how PWDs from other districts are collaborating with public servants.
- * A frank discussion and a clear way forward.
- * To know how EDF/RHP expects the directorate of Health services at districts can assist PWDs.
- * Clear strategies to be adopted to bring Health services closer to PWDs.
- * Expecting funding from EDF/RHP for Health initiatives for PWDs.

EXPECTATIONS OF THE ORGANISERS

- * That discussions would be held openly.
- * That both the technical people (Directors for Health Services in districts) and politicians would be positive as regards integrating PWDs in district health activities and initiatives.
- * That EDF/RHP may show willingness to fund health initiatives for PWDs.
- * That recommendations for the way forward would be agreed upon and later implemented.
- * A report of the proceedings and an agreed way forward.

2.3 Organisers of the workshop:

The workshop was organised by National Union of the Disabled Persons of Uganda (NUDIPU)

It was funded by European Development Fund/Rural Health Programme (EDF/RHP) and was facilitated by Mr. William Nokrach and Hon. Alex Ndeezi. Martin Ssenoga was the rapporteur.

2.4 Participation

The workshop drew together Councillors for PWDs, Representatives of District Unions of PWDs, Secretaries for Social Services for districts, EDF/RHP, District Directors of Medical Services, Ministry of Health and NUDIPU.

Thus, the workshop brought together politicians and technical people from health.

2.5 Duration/Venue:

The workshop lasted for two days. (Friday 27th June and Saturday 28th 1999, at Pelikan Hotel, Mbarara. Participants arrived on Thursday evening.

2.6 Workshop Methodology:

The sessions ran from 9:00a.m. - 5:00p.m.

Discussions on the first day ended at 5:00p.m.

The sessions had short presentations by Ministry of Health, NUDIPU, EDF/RHP, Director of Medical Services and a councillor for PWDs. After these presentations

participants were divided into working groups, which later reported back in the plenary. While in-groups each participant was encouraged to participate maximally and then all participants later benefited from the reports in the plenary.

Reports were followed by general discussion.

Each group had a chairperson who guided the group discussion; and ensured balanced participation in all deliberations, without imposing his own views on members of the group. Each group had a secretary who was responsible for jotting down all issues raised on flip chart papers in a precise way without influencing or changing the meaning; after which present the group response to the plenary within the allocated time.

2.7 Report and follow-up:

The Rapporteur, facilitator and organiser, compiled this report. It is to be shared and circulated to all those who participated in the workshop, those who did not turn up for the workshop and other partners. Follow-up would be by NUDIPU in collaboration with EDF/RHP, more specifically the Programme Sociologist.

2.8. Workshop Agenda:

Below was the Agreed upon Agenda:

Thursday 24th June 1999	-	Arrival of participants from distant Places at pelican Hotel, Mbarara.
Day 1:		
Friday 25th June, 1999 9.00-9.30 a.m.	-	Registration
9.30 a.m. - 10.30 a.m.	-	Introduction and expectations
10.00-10.30 a.m.	-	Presentations (10mins) Secretary for social services Kabale, EDF/RHP, NUDIPU, Bushenyi, Representative of Director for Medical Service Mbarara, Ministry of Health, councillor for PWDs.
11.40 - 12.00 p.m.	-	Tea Break
12.00-12.30 p.m.	-	Group Discussion
	-	What health programmes exist in the Districts.
	-	How are PWDs involved and benefiting in District Health activities and initiatives. (Participants)
1.15 - 2:15 p.m.	-	Lunch Break
2.15p.m. - 5.15p.m.	-	Participants were required to give their own experiences on the current health

activities and initiatives)

- List barriers to access to the services
- What are some of the specific needs of PWDs not addressed by existing programmes?

Day 2:

Saturday, 28th June 1999

- | | | |
|--------------------|---|--|
| 8:30 - 9:00 am. | - | Registration |
| 9: 00 - 10:00 a.m. | - | Presentation for group 2 this group. |
| 10.00 - 10:30 a.m. | - | Tea Break |
| 10:30 - 11:30 | - | General discussion on way forward after hearing presentations from both groups |
| | - | How can PWDs benefit from Programmes Supported by EDF/RHP |
| | - | Way forward |
| 11:30 | - | Closing remarks |
| 12:00 | - | Lunch and Departure |

3. PRESENTATION BY SECRETARY FOR SOCIAL SERVICES - KABALE DISTRICT

There was a ten-minute presentation by the secretary for social services of Kabale District on the Health programmes that exist in Kabale, how people with disabilities are involved and how they benefit from health activities and initiatives.

3.1 Ms. Alice Bakeine, made the presentation from Social Services Kabale.

- Health Services that exist in Kabale District include the following;
- Malaria control Programme
- General health education program
- Immunisation programme (UNEPI)
- Water and sanitation programme
- Curative programme
- Physiotherapy/Rehabilitation Programme.
- Dental Health Programme
- Mental Health Programme
- Family Planning
- Nutrition Programme
- STD/VIPs/AIDS Programme.
- School Health Programme
- Adolescent Sexuality and Reproductive Health
- Safe motherhood Programme
- Health Management Information System (HIMS)
- Vector Control Programme.

HOW PEOPLE WITH DISABILITIES ARE BEING INVOLVED IN DISTRICT HEALTH ACTIVITIES AND INITIATIVES

- a) PWDs are involved in Physiotherapy and Rehabilitation Programme. PWDs benefit from this programme individually.
- b) They are involved in the District Planning process through LC V Councillor representing PWDs and who is on the District Health Sectoral Committee.
- c) They are involved in District Health mobilisation Programme for all Health Activities.
- d) They are involved in sensitising the community leaders and community at large on issues that cause some of the disabilities
- e) They are involved in Health meetings with the Physiotherapist, Mental Health illness workers and others to discuss together the causes, possible preventive measures and even the management of illness of PWDs.
- f) In the rest of the Programmes PWDs, are catered for like any other Ugandan.

However there are barriers, which make PWDs not fully, involved.

1. They are not being well mobilised and sensitised on most of the Health Programmes.
2. Inadequate mobility appliances as most PWDs come from far off areas and when invited for some activities they fail to come because of being unable to move.
3. Funds to most of their needs not available.

3.2 Presentation by NUDIPU

By Mr. William Nokrach (Ag. Executive Director/Vice Chairman NUDIPU)

- NUDIPU was formed in 1987 with a mission of lobbying for equalisation of opportunities for Persons with Disabilities (PWDs)
- To as a unified voice for PWDs in Uganda.
- NUDIPU Programmes include; Awareness raising to eliminate negative attitudes towards PWDs and to sensitise people about the causes of disability and potentials of PWDs.

- Advocacy and lobbying programme, which has resulted into PWDs being represented in Local Government councils, in Parliament and other constitutional bodies.
- Decentralisation Programme: - After recognising the benefits accruing from decentralisation by the Government of Uganda, NUDIPU undertook a decentralisation programme in 1996, funded by the Danish Council of PWDs (DSI). This has resulted into 45 district unions of PWDs in Uganda. NUDIPU is now closer to PWDs than ever before.
- NUDIPU also trains leaders of PWDs to equip them with leadership skills, and skills for self-reliance through training Programmes like IYB -Improve Your Business.
- NUDIPU also gives support to member organisations e.g. Bicycles to District Unions to facilitate mobilisation of PWDs, and mobility appliances to councillors of PWDs and leaders of the District Union. NUDIPU lobbies for the provision of mobility services to PWDs.
- A gender Programme to sensitise women with disabilities about their rights, to raise their esteem.
- NUDIPU also participates in co-ordination meetings with Government and other NGOs.

What NUDIPU does not do.

- Does not provide services it only lobbies and advocate for provision of services for PWDs. NUDIPU memberships are the District Unions of PWDs.

Challenges NUDIPU is facing:

- With more awareness PWDs are demanding for services from NUDIPU.
- Communication with people with hearing impairment/Deaf is still a problem.
- In spite of the enormous awareness that has been done, negative attitudes still exist among society, and this requires more advocacy and sensitisation.
- NUDIPU still needs to lobby for accessibility to public buildings and utilities.
- Poverty levels are very high among PWDs, NUDIPU needs to work out a strategy to tackle this problem.
- PWDs are not involved in planning and decision making at lower levels. There is need for more consultation.

- Few PWDs are working as health workers because of negative attitudes among those responsible for recruiting trainees.

3.3

Presentation Directorate for Medical Services Mbarara By Mr. Sam Masaba.

- Health programmes in Mbarara District include;
- Outreach programmes; assessment centres have been established, sponsored by AVSI and 'OURS.'
- Provision of appliances after assessment. The only problem is that appliances are very expensive. RUHARO eye-centre is providing spectacles to people with eye-problems but at a small cost.
- Other problems include, lack of Braille equipment, physiotherapy services, inadequacy of drugs in Healthy Units. Mbarara also lacks ENT surgeons. Mbarara lacks corrective surgery services after assessment.
- The theatre in a Regional Hospital only handles emergencies because it has only two rooms.
- Family planning services exist but are not accessible to PWDs. Also many of the men in Western Uganda seem to like big families and this hinders family planning.
- All milk from many of the families is sold leaving children malnourished and hence possibility for increased rate of sickness and disability. .
- Women with disabilities are more vulnerable to unwanted pregnancies. Able -bodied men are taking advantage of them.

Recommendations:

- Districts and sub-counties should subsidise mobility appliances. Also Donors could be lobbied for the same.
- More awareness is needed to reduce negative attitudes.
- PWDs need empowerment to interact freely with public servants

3.4

Presentation by Bushenyi Councillor for PWDs By Mr. Baingana Francis

- Most of the Public servants are not co-operative with PWDs. There is need for more sensitisation.

- Many of the Health Servants and Programmes exclude PWDs.
- Many of the Health centres are inaccessible to PWDs.
- Many PWDs shun meetings with Public Servants because they feel rejected by them.
- Many women with disabilities lack information about family planning and Primary Health Care.

There is need to train PWDs to work as Health workers, this will equip them to reach other PWDs with health programmes. E.g. people would be easily sensitised if the person encouraging them to immunise their children against polio were a polio victim himself.

3.5

Presentation by EDF/RHP by Dr. Mohammed Kisubi

- EDF/RHP started working in Western Uganda in 1985. (in 10 districts)
- Work started with renovation of Health Centres and equipping them with facilities and utilities.
- Training Health workers.
- EDF/RHP has an annual budget of 12 million US dollars.

EDF/RHP -areas of support:

- EDF/RHP does not implement, but it only provides resources to districts after getting district work plans.
- Supports Health sector at district level but many district work plans lack a component on disability.
- In future all districts work plans will not be funded by EDF/RHP unless secretaries for social services have approved them.

Specific funding areas:

- Training of Health workers at district level.
- Training of staff in districts according to the specific needs of the district.
- EDF/RHP does not make decisions; it's the Districts themselves.

- Sensitisation and awareness programmes in Health related activities.
- EDF/RHP co-ordinates Health service providers including donors.
- EDF/RHP informs districts how much they are to provide for budgets. In other words it declares how much it will provide to each district for that year.
- EDF/RHP provides transport (Land rovers) for each district for Health activities. Also fuel is provided, bicycles, motorcycles.
- It supports local administration. It deals directly with sub counties, receives sub-county work plans from LC 3 Chairpersons.
- Only supports activities where community support is evident. This is to ensure sustainability.
- NGO support through District Medical Officers.
- Supports Aids related activities but these must be in district work plans.
- Funds essential supplies but these must be in districts work plans.

What has EDF/RHP done for PWDs?

In order for PWDs to benefit from programmes funded by EDF/RHP they must do the lobbying themselves. EDF/RHP is willing to support initiatives of PWDs. Activities and initiatives of PWDs should be channelled through D.M.O.s who should include activities of PWDs in their work plans.

3.6

Presentation by Ministry of Health. (Rehabilitation Section) by Dr.Alice Nganwa

This presentation focused on Rural Health Programme and People with Disabilities-Way Forward.

- Health indicators in Uganda include Infant mortality rate (IMR), Crude death rate, and Maternal Mortality Rate
- Uganda lacks stratified data on PWDs. M.O.H is using estimates based on world-wide surveys. For instance some of the estimates used in the workshop were based on world –wide surveys done in 1980s and early 1990s compiled by Helander.

- PWDs live far away from Health facilities in rural areas, PWDs lack enough Health workers to cater for their specific Health needs. According to Uganda National Health Profile by District 1993, population within 5k.m radius of a health facility is 46.6% in Bushenyi 19.1%, in Kisoro, and 99% in Kampala.
- Rural health facilities are often understaffed. In addition 56% of health workers deployed in rural areas are untrained.
- This unequal distribution of health services is even worse for the rehabilitative needs for PWDs. For example the nearest point where they can get meaningful interventions and drugs may be the district hospital. Where rehabilitative services do exist, they have largely been relegated to NGOs.

Steps taken by M.O.H to improve health services:

- Through the Entandikwa scheme, government has endeavoured to improve the living standards of people.
- The M.O.H has established minimum Health packages for districts, which consist of interventions that address the major cause of burden of disease in our country. This was circulated to participants to enable them get familiar to it and be able to follow-up in their districts.
- PWDs lack information on sexually transmitted infections/HIV/AIDS, and are ridiculed at service points, M.O.H plans to intervene through sensitising health workers about the needs of PWDs and providing appropriate accessible information.
- Many PWDs lack information regarding essential pregnancy and delivery care due to lack of skills to manage Women with disabilities. M.O.H should train health workers how to handle women with disabilities so as to eliminate negative attitudes that hinder women with disabilities from getting access to health facilities.
- Many PWDs face violence especially the women when they go for health services, this calls for education of PWDs so that they can view health centres as Community facilities and laws should be put in place to eliminate discrimination of PWDs.
- Many parents do not take Children with disabilities for immunisation. M.O.H should sensitise parents of CWDs.
- Public latrines are not accessible to PWDs, M.O.H together with all stakeholders need to sensitise the communities to ensure accessibility of latrines to PWDs
- Most health education pamphlets and posters are inaccessible to PWDs

especially the blind who can only access Braille information or tape-recorded information. While the deaf could read, few of them are educated and information via radio excludes them.

Accessible and appropriate messages should be passed to PWDs. Many of the school Health programmes lack a component of screening for disabilities.

Schools should ensure accessibility for CWDs to classrooms and latrines and integrity early screening of children for disabilities.

Disability and Rehabilitation services are inadequate and expensive especially surgery and orthopaedic appliances. There's also lack of drugs, diagnostic equipment. Counselling and little or no counselling. There's need for streamlining rehabilitative health care by implementing the M.O.H package for Essential rehabilitative health care.

Providing Rehabilitative services to PWDs is cost-effective because the result is that PWDs will be able to contribute to community economic activities. It will also restore dignity and respect for PWDs.

REPORT FROM GROUP DISCUSSIONS

- How have PWDs benefited from programmes funded by EDF/RHP?
- PWDs like able-bodied people have benefited from the construction of Health units and the supply of medical equipment.
- Transport facilities to facilitate Health personnel like motorcycle, bicycles, fuel have also contributed to improvement of health services of the general populace.
- By EDF/RHP training health personnel, it's building capacity that will not only benefit the able-bodied but also PWDs. It has also strengthened District Health teams and supported the epileptic drug programme.
- In some districts EDF/RHP has funded protection of water sources, the environment and sanitation.

What barriers exist to the provision of services to PWDs?

- The bureaucratic procedure of accessing funding. All support to NGOs by EDF/RHP is done through D.M.Os. This makes it a bit laborious.
- Beneficiaries are not consulted during planning
- Since EDF/RHP does not decide on what specific activities, funds are to be spent

(this is left to districts) PWDs are marginalised in the implementation of the health programmes.

- Many PWDs still lack confidence to air out their views. This calls for more awareness raising among PWDs.
- Many of them cannot afford to pay for cost sharing in health units.

WAY FORWARD:

- Initiate programmes/projects that should target PWDs. e.g. medical workers should be trained on specific issues of relevancy to PWDs e.g. Physiotherapy or production of mobility appliances.
- People with disabilities be given affirmative action in Health Units implementing Cost-sharing.
- Workshops for capacity building be conducted to equip PWDs with lobbying skills.
- District Unions and Councillors for PWDs should identify areas of concern for PWDs and lobby D.M.Os to include disability programmes in their action plans.
- Attempts be made to promote participation of PWDs in all health activities including planning, implementation and mobilisation.
NUDIPU should share a report of the workshop with relevant stakeholders and encourage them to implement their recommendations.
- A follow-up workshop be organised by NUDIPU to assess progress made in implementing recommendations.
- Participants should share all information obtained from the workshop with relevant people including PWDs, district leaders etc.

Closing

- Hon.Hood Katuramu while closing the workshop thanked EDF/RHP for funding the workshop and hoped that each participant would handle his/her part in the recommendations made. He specifically hoped that quarterly plans from District Medical Officers would demonstrate greater sensitivity to disability issues.
- He thanked participants for their active participation and for demonstrating a spirit of voluntarism and desire to serve the disability community.
- He thanked NUDIPU for fundraising and organising the workshop.

Received 6/8/99



National Union Of Disabled Persons of Uganda

Plot No. 530, Kisasi Road - Bukoto

P.O.Box 8567
Tel/Fax: 540179
KAMPALA
UGANDA.

Our Ref:

Your Ref:

22nd July 1999

Date:.....

Dr Alice Nganwa
Ministry of Health
Rehabilitation Section

Dear Alice,

RE: REPORT OF THE PROCEEDINGS OF THE MBARARA WORKSHOP

I would like to thank you very much for the excellent presentation you made in the workshop. It was an eye-opener for all of us.

Thank you for your invaluable cooperation with NUDIPU.

I now wish to share with you the report of the proceedings of the workshop.

Yours sincerely,


Alex Ndeezi
Chairman NUDIPU.